Knowledge and information needs of informal caregivers in palliative care: A qualitative systematic review

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Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review

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Objectives: To review current understanding of the knowledge and information needs of informal caregivers in palliative settings. Data sources: Seven electronic databases were searched for the period January 1994–November 2006: Medline, CINAHL, PsychINFO, Embase, Ovid, Zetoc and Pubmed using a meta-search engine (Metalib®). Key journals and reference lists of selected papers were hand searched. **Review methods:** Included studies were peer-reviewed journal articles presenting original research. Given a variety of approaches to palliative care research, a validated systematic review methodology for assessing disparate evidence was used in order to assign scores to different aspects of each study (introduction and aims, method and data, sampling, data analysis, ethics and bias, findings/results, transferability/generalizability, implications and usefulness). Analysis was assisted by abstraction of key details of study into a table. **Results:** Thirty-four studies were included from eight different countries. The evidence was strongest in relation to pain management, where inadequacies in caregiver knowledge and the importance of education were emphasized. The significance of effective communication and information sharing between patient, caregiver and service provider was also emphasized. The evidence for other caregiver knowledge and information needs, for example in relation to welfare and social support was weaker. There was limited literature on non-cancer conditions and the care-giving information needs of black and minority ethnic populations. Overall, the evidence base was predominantly descriptive and dominated by small-scale studies, limiting generalizability. **Conclusions:** As palliative care shifts into patients' homes, a more rigorously researched evidence base devoted to understanding caregivers knowledge and information needs is required. Research design needs to move beyond the current focus on dyads to incorporate the complex, three-way interactions between patients, service providers and caregivers in end-of-life care settings. *Palliative Medicine* (2008); **xxx**: 1–19

Key words: caregivers; caregiver needs; knowledge and information needs; research design

Introduction

Given the choice, most people say that they would prefer to die at home. Research conducted for Marie Curie Cancer Care suggested that the proportion of individuals in the UK who would like to die at home was 64% ($n = 2000$),[1] while a recent survey for the BMJ suggested a figure of 74% ($n = 1511$).[2] These findings largely confirm earlier research: a systematic review of studies of preferred place of death established that well over 50% of patients wanted a home death.[3] However, the actual place of death of cancer patients and those with other terminal conditions in the UK does not currently correspond to patient preference. In 2000, only 23% of cancer deaths in the UK took place in the patient's own home compared with 55.5% in hospitals, 16.5% in hospices and 5% in other locations.[4]

Developing palliative care services to enable a greater number of people to die at home has become a key policy goal in the UK. The report of the recent Government Select Committee on palliative care in England and Wales argued that home-based care should be promoted, as it offers terminally ill patients greater choice and potentially improves their quality of life.[5] Indeed, a recent meta-evaluation of the effectiveness of palliative care teams suggested evidence of benefit was greatest for patients receiving home care.[6] There is also an economic argument in favour of moving end of life care into the home: research

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suggests that the costs of providing such care may be half that currently spent on hospital services for the dying.[7]

Moving palliative care into patients' homes raises some important challenges for service providers. Prominent among these is the need for service providers to work effectively with informal caregivers. Informal caregivers (especially close family relatives) frequently play a crucial role in the provision of palliative care. Gomes and Higginson's recent systematic review has demonstrated that the provision of extended family support is an important factor in determining whether a terminally ill patient dies at home.[8] Understanding caregivers' needs, their varied experiences and the complex interactions between caregivers, health care professionals and patients is important if effective end of life care is to be provided. Published reviews have examined a range of topics in relation to these themes, including which service interventions are most effective in helping caregivers in a range of different settings.[9–11] However, there has been no recent systematic review of the disparate evidence base covering the knowledge and information needs of caregivers in end of life situations. With the development of home-based palliative care services, it is important that caregivers understand the nature of a patient's illness, the range and scope of service provision and their own role and competencies in palliation. This systematic review assesses the research literature on these knowledge-related needs of caregivers.

Method

The following databases were searched for the period January 1994–November 2006: Medline, CINAHL, PsychINFO, Embase, Ovid, Zetoc and Pubmed, using a meta-search engine (Metalib®). This period was selected as it allows coverage of the time period in which electronic journal publishing became more widespread in addition to allowing a focus upon recent practice developments with regards to carers, which have developed in particular over the last decade. Keywords included: carer, caregiver, palliative, terminal, end of life and related phrases. This approach was supplemented by hand searching of leading journals (*Palliative Medicine, Journal of Palliative Care and International Journal of Palliative Nursing*) and systematic checking of the reference lists of all identified papers. Included papers were peer-reviewed English language, journal articles within the search period. Review papers, commentaries, editorials, letters, books, reports and theses were excluded from the study.

Abstracts of papers meeting these inclusion criteria were obtained and independently reviewed by two members of the review team. Because of the volume and variety of papers identified, a subset of articles dealing with issues relating to caregiver knowledge and information needs were selected for inclusion in this review. Full papers were subsequently obtained and independently reviewed by at least two researchers from a dedicated team of four (AD, AO, MAL, RP). Details were entered into a table summarizing the focus, design, main outcomes, weaknesses and generalizability of each study.

The inherent variability in research design (including both qualitative and quantitative studies) and outcome measures characteristic of palliative care research, rendered the use of conventional systematic review methods – principally designed for the evaluation of randomized control trial (RCT) studies – inappropriate. The review was therefore undertaken using a published, validated scoring system for systematically appraising more disparate evidence, including qualitative studies.[12] This methodology assesses eight study components: introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability and generalizability, and implications for policy and practice. Each component is given a score ranging from 1 to 4 (good=4, fair=3, poor = 2 or very poor = 1), generating a potential maximum total of 32.

During the review process, the papers were independently scored by two researchers and where agreement could not be achieved, consensus was obtained via reference to a third team member. Seventeen papers were subsequently excluded, as on closer inspection they did not fully meet the inclusion criteria, resulting in a systematic review of 34 papers (Table 1).

Analysis was based on comparison of study details, including design, sample and setting, research focus, key results/outcomes, implications and weaknesses, as recorded in Table 1. The analytical process focused in particular on the identification of similarities and differences in relation to these areas. Subsequent realization of the heterogeneity of these factors including the predominantly descriptive nature of design prevented the undertaking of a meta-analysis.

Results

Study selection and characteristics

Thirty-four papers fulfilled the inclusion criteria, incorporating a focus on caregiver knowledge-related needs, including communication, information and education.[13–51] Study focus included pain management, in particular inadequacies in knowledge and the impact of education,[14,16,30,31,35–37,40,44,46] caregiver–patient communication,[15,19,21,22,27,39] caregiver–health professional communication,[13,18,25,45] caregiver needs,[23,26,29,32,34,38] service-related communication and information,[20,33,41–43] and the implementation and development of interventions.

Table 1 Key details and scores for included studies

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
Aldred, *et al.* (2005)	Advanced heart failure: impact on older patients and informal carers	Qualitative interviews of patient–caregiver dyads	10 patients with stage II–IV heart failure and their caregivers attending a district general hospital in the UK	Explores the impact of heart failure on patient and caregiver	Negative impact of illness compounded by lack of understanding of the condition and fragmented care provision, facilitated by poor communication, in particular lack of time	Greater need for communication especially around prognosis	Small sample size, not all palliative. Response bias as participants in better health than non-participants	21
Aranda, *et al.* (2004)	Barriers to effective cancer pain management: a survey of Australian family caregivers	Descriptive, exploratory cross-sectional study of a cohort of family caregivers recruited over a one-year period. Univariate and bivariate analysis	75 caregivers of cancer patients attending outpatient oncology clinic in a public hospital. Australia	Investigates family barriers to effective pain management	Uncertainties about addiction, disease progression, side effects, and tolerance	Need to raise awareness of caregivers about pain management	Self-reported, small sample size, limitations in generalizability	21
Beach (1995)	Caregiver discourse: perceptions of illness-related dialogue	Qualitative study using semi-structured interviews and content analysis methodology	10 caregivers in a hospice, semi-structured interviews. USA	To examine how caregivers perceive their communication with dying family members	Six sub-categories found: caregiver denial, patient denial, second guessing, previous discourse, illness-related dialogue, bereavement	Need to improve communication in similar situations and track various communication interventions	Small sample, all female (restricts generalizability), single data source (no triangulation)	20
Berry and Ward (1995)	Barriers to pain management in hospice: A study of family caregivers	Quasi-experimental study using validated questionnaire of primary caregivers of terminally ill cancer patients eligible for hospice care. Univariate and bivariate analysis	37 caregivers participated (further sample characteristics given). Recruited through home care-based hospice programme in urban mid-western USA	To examine concerns about reporting pain and using analgesics in a sample of primary care givers of patients receiving hospice care	Caregivers reported various concerns about treatment of pain (eg, addiction, side effects, disease progression). Older and lower educated caregivers more likely to believe reporting pain distracts physician from treating cancer	Understanding caregiver perspectives on pain is important in developing hospice services and services in other settings	Small sample size. Interviewing caregiver and patient together may have distorted results	14
Cameron, *et al.* (2004)	A brief problem-solving intervention for family caregivers to individuals with advanced cancer	Descriptive: pre- and post- using several tools and an educational intervention in the middle (mean: 4.8 weeks). Analysis using	41 out of 105 caregivers, Canada	Evaluation of an educational intervention. Measured: demographics including age, sex and marital status, problem solving approach,	Problem solving methods (defining problem, professional assistance, help patient, obstacles, adjusting). No difference detected unless emotional tension	Problem solving interventions may have some benefits	Low uptake rates, no control group so improvements may have taken place naturally	20

(continued)

Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
		t-test and chi-square		emotional well being, caregiver assistance and self-efficacy				
Caron, *et al.* (2005)	Decision making at the end of life in dementia: how family caregivers perceive their interactions with health care providers in long term care settings	Qualitative in-depth interviews adopting grounded theory approach	24 caregivers of family members with late stage dementia. Recruited from geriatric institute and long-term care centres. Canada	To examine the experience and preoccupations of family caregivers about end of life issues and in particular about treatment decision-making processes	Family caregivers seek a personalized relationship with care providers. The majority expressed a need to meet more often with the care team to provide an understanding of the evolution of the condition. Trust was a key element in the caregiver – professional relationship and was facilitated via regular contact and information provision	Health care providers should facilitate a proactive caregiver approach by offering opportunities for communication. Long-term care should incorporate a philosophy of partnership with the caregiver	Relatively small sample. Retrospective interviews	23
Clayton, *et al.* (2005)	The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end of life issues	Qualitative study combining focus groups, face to face interviews and telephone interviews	22 health professionals, 24 caregivers and 19 patients recruited from specialist palliative care services. Australia	Perspective of health professionals, patients and caregivers on the provision of information regarding prognosis and end of life care	Consistent information important, so that both patient and caregiver had the same understanding of what to expect. Variation in preference regarding information dissemination with particular regard to prognosis. Problems with using interpreters were highlighted. For family interpreters concern was raised regarding the power this gave the interpreter to withhold information	Highlights importance of checking individual needs of patient and caregiver regarding prognostic and end of life information as they can be different	Small sample size. Poor generalizability. Educational background of caregivers higher than the national average	20
Exley, *et al.* (2005)	Palliative care in the community for cancer and end-stage cardio-respiratory disease: the views of patients, lay-carers and health care professionals	Qualitative study (using semi-structured interviews and focus groups) of patients, caregivers and health care professionals, comparing primary palliative care for people with advanced cancer and those with end-stage cardio-	50 interviews, relating to 29 patients, most with informal caregiver also present. First interview and then follow up in most cases. Service providers' views elicited from focus groups (GPs, district nurses, specialist palliative care	Comparison of primary palliative care provision for cancer and end-stage cardio-respiratory patients	People with end stage cardio-respiratory disease less likely to receive full and easily understood information; to be aware that they are dying and to receive district nursing care than cancer patients. Also more likely to experience financial difficulties. They are the 'disadvantaged dying'	Findings echo other studies. Need to develop services and increase uptake/access	Small-scale study that is not easily generalizable. Some problems identifying participants and a longer gap needed between interviews	21

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Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
		respiratory disease	community nurses and occupational therapists). Number of participants not specified					
Field, *et al.* (1995)	Terminal illness: views of patients and their lay carers	Cross-sectional, descriptive. Semi-structured interviews conducted with patients and caregivers	Interviews with 28 terminally ill patients at hospice and their caregivers, Leicestershire	Comparison of patient and caregiver perceptions of patient experiences leading to hospice admission: symptoms, activities of daily living and perceptions of care	Agreement on the perception of need for daily activities; divergence in psychological symptoms, distress and the number of main symptoms	Information obtained from caregivers is valid proxy	Small sample size, questions regarding reliability of measures)	23
Fine and Busch (1998)	Characterization of breakthrough pain by hospice patients and their caregivers	Descriptive study using survey and qualitative methods comparing breakthrough pain experienced by patients and caregivers perceptions of it	22 hospice patients with advanced cancer and caregivers (19 experienced breakthrough pain and therefore included) Recruited through Hospice in Salt Lake City, Utah, USA	Investigates the nature – occurrence, duration, perception of intensity, amount and time of relief – of breakthrough pain (intense episodic pain) experienced by patients; compares with caregivers perceptions	86% of sample experienced breakthrough pain, 2.9 times per 24 hours. Mean pain intensity of 7 (1–10) lasting average of 52 minutes and 30 minutes until relief. Caregivers underestimate experience of breakthrough pain in patients	Suggests need to develop oral analgesic provision for more optimal management of breakthrough pain	Small sample size limits generalizability. Breakthrough pain may have been under/ over estimated, qualifying conclusions	14
Fukui (2004)	Information needs and the related variables of Japanese family caregivers of terminally ill cancer patients	Descriptive, structured interview/quasi-experimental design using questionnaires	66 Japanese caregivers in a pall care unit. Measures: demographics including age and sex, patient functional status, situational variables. Rating of information need	Examined the information needs of family caregivers of terminally ill cancer patients	'Disease-related' and 'care-related' informational needs; 73% wanted disease-related info (cancer, treatment, prognosis) +<50% required care-related info; determinants have been analysed	Providing information to caregivers, weak generalizability. Younger family caregivers may require greater focus from HPs on their information needs regarding the patient's	Small convenience sample, low response rate	23

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Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
						disease and treatment		
Gagnon, *et al.* (2002)	Delirium in advanced cancer: a psycho educational intervention for family caregivers	Mixed: qualitative and quantitative; descriptive observational	Three phases: generating themes (21 caregivers+11 professionals), developing first version of brochure (20 caregivers), intervention (58 control and 66 caregivers), Canada	Evaluation of the implementation of a psycho educational intervention in a palliative care hospice to help family caregivers cope with delirium	Intervention had some positive effects on caregivers' perception about delirium, especially if delivered in earlier phase of cancer – had greater knowledge and experienced less misunderstanding. No improvement in mood	Integrated in palliative care services in the region, satisfying caregivers' information needs – should be targeted in use	Non-randomized, small sample	22
Harding, *et al.* (2004)	Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service	Quasi-experimental. Prospective and observational evaluation, using both qualitative and quantitative methods. Involved comparison of intervention with non-intervention group (ie, like control). Used various validated outcome measures. Univariate and multivariate analysis of results	73 caregivers: 36 attended the intervention; 37 declined; but attrition of numbers in follow-up sessions. Study undertaken with two palliative care home services in London	Evaluation of service intervention "The 90 minute group" which combined informal multiprofes-sional teaching with facilitated peer exchange and support	Evaluation suggested that patients in intervention group gained from support and knowledge provided by 90- minute group, awhile they participated. Attrition (of nos. involved) prevented analysis of impact on 'global psychological scores'	Study demonstrates need for rigorous evaluation of interventions for caregivers (but also demonstrates some of problems). Lessons for future evaluations discussed	Modest sample size with attrition problems. Some of limitations not recognized until post study	18
Harrington, *et al.* (1996)	Needs of caregivers of clinic and hospice cancer patients	Prospective, correlational study involving caregiver completion of the Home Caregiver Needs Survey (HCNA)	55 caregivers of clinic cancer patients (25) and hospice patients (30); in rural and urban setting in USA using the HCNA tool. Mean ages: 51 and 56 years respectively, 17 female in the	Comparison of the self-identified needs of caregivers of patients who were either clinic or hospice based	Information and spiritual needs as the most important needs. Spirituality suggested as key element in the caregiver's coping strategies in taking care of the cancer patient	Providing information needs, referring to appropriate community agencies, helping caregivers to satisfy their needs. Information should be individualized	Failure to control for type of cancer diagnosis, length of disease process and patient level of dependency. Sample size too small	25

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Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
			latter and 23 in the former. 8 were spouses in the former and 15 were in the latter. Measures: caregiver needs, demos			for the caregiver based on the stage of illness and the concerns of the caregiver. Suggests development of information assessment instruments		
Hauser, *et al.* (2006)	Who's caring for whom? Differing perspectives between seriously ill patients and their family caregivers	Quantitative study comprising administration of survey to both individuals in each dyad	988 patients, 893 caregivers, multiple disorders including cancer, heart disease and COPD. USA	Aims to investigate concordance between patient and caregiver views regarding end of life care	52% agreement regarding levels of pain. 57% agreement regarding levels of patient activity. Lower proportion of caregivers (15%) reported needing further care support at home compared to patients (30%). Overall patients reporting higher care needs that did caregivers. 66% agreement regarding high level of trust in physician, for remainder, majority of cases, caregiver had less trust than patient. 48% agreement regarding clarity of information on prognosis, again for majority, caregiver was more dissatisfied. Similar pattern for information relating to side effects (51% agreement) and whether physician listened (62% agreement)	Professionals need to recognize that patients report different – and often higher – care needs than the caregivers	Excluded patients with dementia and AIDS	22
Hudson, *et al.* (2002)	Intervention development for enhanced lay palliative caregiver support – the use of focus groups	Phase one (intervention development) of three-stage strategy for developing nursing intervention. Qualitative focus group study (moderated); code-based content analysis of data	Three focus groups: palliative care nurses (7 participants); bereaved caregivers (8 participants); current caregivers (6 participants). Melbourne, Australia	Needs-based study towards development of new nursing intervention focusing on guidance and support provided for lay caregivers	Caregivers felt unprepared in role and wanted more support from health professionals: verbal and written information on how to care; how to plan and prepare for future	Findings confirm prior research and feed into development of new nursing intervention (being evaluated by RCT study)	Small sample, not easily generalizable	23
Jansma, *et al.* (2005)	Support requirements for caregivers of patients with	Descriptive, cross-sectional; qualitative and survey	26 interviews (in two stages) and 50 caregivers in survey. Netherlands	To identify the needs of caregivers of palliative cancer patients	Caregivers' needs: communication, practical information, caregivers' health and social network	Providing support programmes to respond caregivers' needs	Majority of the data were retrospective, suggesting recall bias and	20

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Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
	palliative cancer			and how to address these needs with a support programme			also the questionnaire was completely self-devised without any validation	
Kasanowski (1998)	Family caregivers medication management of symptoms in patients with cancer near death	Qualitative study using in-depth interviews. Grounded theory method of analysis (constant comparative method)	17 female caregivers of patients with cancer. USA	Aim to understand the process of medicating for management of symptoms, in cancer patients near death, from the caregiver perspective	Degree of uncertainty in caregiver role, increased by confusion about the different types of medication, indications for their use, time for medication administration and the desired effect on the patient. Confidence increased via verbal and/or written information and ongoing nursing evaluations to familiarize caregivers with the medications	Need for better quality information to enable family caregivers to manage medication	Small sample size, limited ethnic mix and single hospice	16
Keefe, *et al.* (2005)	Partner guided cancer pain management at the end of life: A preliminary study	Random assignment of pairs to either standard care or partner guided pain management training (nurse led home visits focusing on education around pain management and enhancement of coping skills). Multiple measures taken via telephone interview	78 cancer patients and their caregivers recruited from two cancer centres. 41 assigned to intervention, 37 to standard care. USA	Test the feasibility of a new, partner guided pain management training protocol that integrates educational information about cancer pain with systematic training of patients and partners in cognitive and behavioural pain coping skills	No significant treatment effects for patients ratings of usual pain [$F(1,54) = 1.21$, $P = 0.028$] and worst pain [$F(1,56) = 0.81$, $P = 0.037$]. Partners receiving the intervention reported significantly higher levels of self-efficacy for helping the patient control pain [$F(1,53) = 8.14$. $P = 0.006$] and for controlling other symptoms [$F(1,53)$. $P = 0.012$].	Highlights the value of partner and patient focused interventions in improving partner self-efficacy and therefore the potential to improve pain management	Low response rate suggests potential bias. Relatively small sample, in light of drop out rate	22
Kessler, *et al.* (2005)	Social class and access to specialist palliative care services	Cross sectional survey and subsample of in-depth interviews with caregivers	960 cancer deaths reviewed 1999–2002. Subsample of 18 caregivers completed in-depth interview. UK	Determine the association between social class and place of death. Qualitative focus on the experience and beliefs of caregivers of patients of lower socio economic status, in	Anxiety was influenced by level of available information and associated perception of control. Most caregivers described a decrease in anxiety when they were able to access high-quality information. Shared information resulted in lower levels of caregiver anxiety. In contrast, some patients kept exclusive control of information by always seeing the doctor alone, leaving their caregivers to search for their	Among lower socio-economic classes, caregiver anxiety will be lower in instances where information is share between caregiver and patient	Small sample size. Variable time between bereavement and interview and nature of relationship between patient and caregiver may impact considerably upon generalizability	17

(continued)

Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
				particular anxiety and perceptions of control	own second hand information, often without success. These differences were not class related			
Koffman and Higginson (2001)	Accounts of carers' satisfaction with health care at the end of life: a comparison of first generation black Caribbeans and white patients with advanced disease	Survey-based study comparing the satisfaction with health care at the end of life of informal caregivers of Black Caribbean and 'white' patients with advanced progressive disease during last year of life. Used retrospective (i.e post death) survey (structured interview, but included some open question for qualitative analysis) as utilized in other studies; includes univariate statistical and qualitative content analyses	Surveyed 50 caregivers of Black Caribbean (Caribbean born) and 50 caregivers of 'white' (UK born); further characteristics of sample described in paper. Survey took place in inner-London boroughs of Lambeth, Southwark and Lewisham, UK, December 1997 to November 1998	Comparison of informal caregivers of Black Caribbean and 'white' patients satisfaction with service provision in both primary care and acute settings among	A larger proportion of respondents representing the view of black Caribbean patients expressed dissatisfaction with care than white patients. Particularly the case in primary care settings. Fewer black Caribbean patients accessed specialist palliative care services or hospices	Results suggest need for health care professionals to communicate more fully with caregivers and patients; further education and training of health care professionals in principles of inclusive palliative care	Relatively low response rates. Satisfaction measures were a relatively insensitive tool for health service evaluation	22
Lecouturier, *et al.* (1999)	Lay carers' satisfaction with community palliative care: results of a postal survey. South Tyneside MAAG Palliative Care Study Group	Feasibility study, using retrospective postal questionnaires to assess the satisfaction of caregivers with services provided for end of life cancer patients. Psychometri-cally developed postal	156 completed the survey (44% response from 255 contacted). Identified via death register. Stratified sample. South Tyneside, UK	Investigates the quality of information provided by health professionals and the quality of services from perspective of lay caregivers	(a) Substantive: information provision deemed unsatisfactory and dissatisfaction at care provided by hospitals district nurses and GPs was common. (b) Methodological: Postal questionnaire is a valid and cost effective method for assessing the quality of care	Survey offers baseline against which improvements in care can be measured	Relatively low response rate from questionnaire. Study was retrospective and caregiver assessments may have been affected by post-bereavement psychological status. District	21

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Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
		questionnaire (described in another paper). Univariate and bivariate analysis of results					(ie, locally) based study	
Lin (2000)	Barriers to the analgesic management of cancer pain: a comparison of attitudes of Taiwanese patients and their family caregivers	Quasi-experimental study using validated questionnaire surveys, pain inventories and a performance status scale to assess barriers to pain management	159 dyads of oncology outpatients and primary care givers participated (n = 318). Carried out in Taipei, Taiwan. Not stratified	To compare attitudes on barriers to pain management between patients and caregivers; to discover if barriers related to hesitancy to take analgesics; to see if attitudinal barriers predicted adequacy of analgesics used	Concerns among both groups about taking/ administering analgesics (positively correlated). Those with higher levels of concern used inadequate analgesics. Family caregiver concerns were a predictor of inadequate management of cancer pain	Research suggests need for educational interventions to encourage optimal use of analgesics to ensure pain management	Local study. Limitations associated with validity of hesitancy (to take analgesics) measure. Study only able to demonstrate associations and causal relationships	19
Lin, *et al.* (2001)	Life-extending therapies among patients with advanced cancer: patients' levels of pain and family caregivers' concerns about pain relief	Quasi-experimental study using validated questionnaire surveys and pain inventories, to assess experience of pain and caregivers' concerns	40 pairs of patients with advanced cancer and their caregivers (n = 80) recruited from inpatient oncology unit in Taipei, Taiwan. 52% were receiving chemotherapy or radiotherapy	How prevalent is use of life-extending therapies? Is there a relationship between use of therapies and levels of pain? Do caregivers who patients receive therapies have less concern about pain management than those who do not? Are concerns related to hesitancy in using analgesics?	Those who receiving therapies had lower pain levels. All caregivers had concerns about administering analgesics and reporting pain, but less the case where receiving therapies. Concerns about pain were related to reluctance to report it	Patients not receiving therapies may have inadequate pain control. Educational interventions concerning pain management required along with development of palliative care	Local study based on relatively small convenience sample of patient–caregiver dyads	16
Lin, *et al.* (2000)	Identifying attitudinal barriers to family management of	A quasi-experimental study using validated questionnaire	80 pairs of palliative care inpatients with cancer and their primary family	Which attitudes among family caregivers function as barriers to pain	Caregivers had concerns about reporting pain and administering analgesics in relation to disease progression, p.r.n. and possible side effects.	Barriers to pain management exist among informal caregivers and	Local study based on modest sample. Pain Management Index tool used	18

(continued)

Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
	cancer pain in palliative care in Taiwan	survey and pain inventory tool to investigate barriers to pain management. Univariate and bivariate analysis	caregivers (n = 160), recruited from inpatient palliative care units in two medical centres in Taipei, Japan	management? How do barriers impact on hesitancy to report pain and administer analgesics? What is relationship between attitudinal barriers and adequacy of analgesics used by patients	Older and less educated caregivers had stronger concerns (barriers). Level of caregiver concern related to reluctance to administer analgesics	education programme is required to address the problem	is questioned by the authors	
Lin and Tsao (2004)	Information needs of family caregivers of terminal cancer patients in Taiwan	Descriptive/ quasi-experimental, cross-sectional	90 caregivers of cancer patients in hospice or palliative unit, Taiwan; using two scales. Measures: demos, information needs and experiences, and attitude scale.		Information needs in order: patient's disease, caregiving, palliative care, social welfare, psychological issues and spiritual care	Providing information needs, using the Information Needs Questionnaire as a valid tool	Potential for redundancy in measure.	24
Lobchuk and Vorauer (2003)	Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences	Descriptive, cross-sectional survey	80 cancer patients and 80 caregivers (ie, n = 160) Hospice inpatients in Taiwan	Caregivers concerns about analgesia as barrier to management of pain	Caregivers' estimates were closest to patients' when asked to imagine the patient's feelings	Limited, technical implications only, but does highlight the technical problems involved in using caregivers as a proxy for patients	Local study. Sequencing of different reporting exercises may have biased caregiver perspective. Limited generalizability of findings	20
Mazanec and Bartel (2002)	Family caregiver perspectives of pain management	Descriptive, qualitative: case study analysis	Case study of female with metastatic cancer	To illustrate the experiences of a caregiver in the process of pain management and identify lessons to be learned	Education decrease the fear of addiction in pain management	Multi-disciplinary work, empowering family caregivers	Single case study design – limitations in generalizability	9
Milberg, *et al.* (2003)	Advanced palliative home care: next-	Qualitative, cross-sectional study using postal questionnaire	217 consecutive bereaved caregivers, Sweden. Open	To identify what aspects of advanced palliative home	Service aspects (staff, accessibility, spectrum of services) and comfort (feeling secure, being in the centre, sharing caring, being	Improving caregivers-professionals communication	Questionnaires distributed up to seven months post	24

(continued)

Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
	of-kin's perspective		ended questionnaire	care are important to next of kin	at home). Positive staff-related comments (continuity, reliability, competence, sharing of care and recognition of patient and next of kin wishes, expertise, attitude and communication). Positive service-related comments (24-hour accessibility, making it possible to remain at home)		death, creating potential recall bias	
Seamark, *et al.* (1998)	Dying from cancer in community hospitals or a hospice: closest lay carers' perceptions	Quasi-experimental retrospective study using structured interview or questionnaire to compare quality of terminal cancer care in community hospital with that in a hospice. Univariate and bivariate analysis	91 caregivers whose patient had died in community hospital and 70 who had died in a hospice (ie, n = 161) in East Devon/Exeter, UK	Investigation of quality of service provided by community hospitals in comparison to hospices (derived from views of informal caregivers)	Caregivers rated hospice care as excellent; 40% suggested improvements possible in community hospitals. Key criticisms of latter: communication problems, lack of nursing staff, lack of bereavement support. Caregivers of patients in hospices, more likely to be present at time of death	Potential for making improvements in community hospitals in terms of communication skills of professionals, more professional training in end of life care and bereavement	Local, single site study with limited generalizability. Analysis of data derived from different methods: interview vs questionnaire	21
Spruyt (1999)	Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers	Descriptive, qualitative, retrospective	18 interviews with ethnic minority caregivers, London. Range: death to interview = 16–96 months; translators used		Findings about communication in the last days, symptom control, preparation for death, spiritual care, impact on caregivers, bereavement, social services. High levels of spiritual care throughout, variation in translation ability in line with family member ability to speak English (often left children with burden), mixed views on whether patient should be told prognosis. HP team viewed positively. Preference for burial abroad created financial strain	Provision of care for Bangladeshi community. Need for palliative care team awareness of social dynamics and traditional values. Must recognize preference for homeland burial	Not fully taped and transcribed. Interview was member of community-professional interpreter in only 4 cases	20
Terry, *et al.* (2006)	Experience of dying: concerns of dying patients and of carers	Qualitative, interview and focus group based study	36 hospice patients, 18 caregivers of patients within the palliative care service (retrospective experiences – patient died	Comparison of patient and caregiver reflections on process of care with particular regard to; physical and emotional	Privacy and Autonomy: patients highlighted their preference to censor information prior to sharing it with families/ caregivers. Caregivers believed that they should be provided with complete information about the patients illness, even when the patient explicitly	Highlighted the need for information regarding patient and caregiver views on confidentiality of info to be	Small sample	23

(continued)

Table 1 *(continued)*

Author and date	Article title	Design	Sample and setting	Research focus	Results/outcomes	Implications	Weaknesses	Score (max 32)
			between six months and four years previously). Australia	concerns, information and decision making.	refused to share the info with them. Caregivers also had detailed and practical concerns about medication; timing, dosage, titration with symptoms	gathered to ensure patient and caregiver needs were met. Multiple actions are outlined with regards to the improvement in info provision at key stages in the patient trajectory in particular prior to death		
Waldrop, *et al.* (2005)	Final transitions: Family caregiving at the end of life	Qualitative study using semi-structured in-depth interviews	74 caregivers of patients in terminal stage of illness with cancer. USA	Exploration of end stage care giving, in particular needs associated with transition	Quality of interaction between caregiver and physicians was highly variable particularly in terms of the extent to which they explained the details of the situation. Caregivers functioned as the executive for the patient and therefore negotiated assistance for the patient, facilitated secondary support, interpreted info etc. Caregivers face practical problems including maintaining employment and dealing with financial concerns	All professionals should carry out an initial assessment of the caregiver's perspective and what level of information they desire	Limited to hospice care, reduces transferability to other populations. Small percentage of ethnically diverse caregivers limits the conclusions that can be drawn regarding cultural variation and applicability	25
Ward, *et al.* (1996)	Concerns about analgesics among patients and family caregivers in a hospice setting	Quasi-experimental study comparing patient and family caregivers concerns about analgesics. Used validated questionnaire to measure concern – 'Barriers Questionnaire'. Includes univariate and bivariate analysis	35 dyads of patients and caregivers (ie, n = 70) attending hospice at home programmes in Mid West and East Coast USA	To compare patient and caregiver concerns about the use of analgesics (eg, fear of addiction, worry about tolerance, worry about side effects)	There was no correlation between patients' concerns and caregivers concerns, suggesting that one member of the dyad has greater concerns than the other	Critical that clinicians attend to both patients and caregiver with respect to assessment, and intervention. Further research needed to see how concerns change over the duration of the illness	Relatively small, homogenous sample. Patients and caregivers in more advanced stage of illness may have under-represented. Reliability of some of Barrier Questionnaire scores low	23

[17,24,25] Research was undertaken in a variety of settings including: patients' homes, hospices, outpatient oncology clinics, community hospitals and in other community institutions. Studies were carried out in a wide range of locations: UK,[13,20,21,25,32–34,42,43] USA,[15,16,22,26,27,30,1,40,45,46] Taiwan,[35–38] Canada,[17,18,24,39] Australia,[14,19,28,44] Japan,[23] the Netherlands[29] and Sweden.[41] Twenty-four papers dealt solely with cancer, while the remaining 10 included patients with a range of conditions as well as cancer, including cardio-respiratory illness, circulatory disease, renal failure, chronic obstructive pulmonary disease (COPD) and dementia.[13,15,18,20,21,25,27,33,41,44]

Critical appraisal of included studies

The majority of studies deployed a descriptive cohort design; 13 used questionnaires/surveys (the majority including non-validated scales), nine used interviews/focus groups and an additional five used both methods. In addition, three studies utilized a descriptive comparative design (comparing either an intervention with a control or comparison of a patient and a caregiver). A further three studies used an exploratory grounded theory approach (interview based) and another adopted a case study methodology. Associated weaknesses included: poor generalizability, opportunistic sampling, frequent use of non-validated instruments, high potential for confounding due to descriptive nature of studies, limited information on causal relationships, and response and recall bias. A summary of sample sizes and critical appraisal framework scores is presented in Table 2.

Outcomes of included studies

Caregivers reported multiple concerns and areas of inadequate knowledge in relation to pain management including understanding of side effects, disease progression, addiction and tolerance.[14,35–37] Concerns were greatest among older caregivers and those with less education.[16,37] Poor correlation was reported between caregiver and patient concerns regarding pain management.[46] Confusion around medication use focused in particular upon uncertainty in the caregiver role and practical concerns regarding timing of administration, dosage and titration of dosage to treat increasing symptoms.[30,44] Life-extending therapies and increased education were found to improve pain management via such outcomes as decreased caregiver fear of addiction.[36,40] Ongoing health professional evaluation of medicine use and increased verbal and written information in line with caregiver need were found to enhance understanding.[30] In response, recommendations highlighted the value of a multi-disciplinary approach to care with a particular focus upon increased education to improve understanding and empower caregivers.[14,30,35–37,40] Caregiver self-efficacy regarding symptom control was significantly increased following caregiver-guided pain management training via nurse-led home visits, although no significant change in treatment effects for patients was reported.[31] In addition, studies suggest that staff must attempt to understand the varying perspectives of caregivers and attend to both caregiver *and* patient information needs in pain management.[16,46]

Table 2 Critical appraisal framework scores and study sample sizes

Mean appraisal score (out of possible 32)	20
Range (appraisal score)	9–25
Sample size ≤50	11
Sample size >50 but ≤100	14
Sample size >100	9

Studies reported variation in patient and caregiver consensus with regard to a range of issues, including: perceptions of physical and psychological symptoms; patient distress and their experience of pain; level of home support required and satisfaction with physician trust; clarity of information and listening skills, with the caregiver often displaying higher levels of dissatisfaction with regards to the latter.[21,22,27,39] Caregiver–patient discourse was characterized by a range of themes including denial, second guessing, previous communication styles, illness-related dialogue and bereavement.[15] Consensus was also limited with regards to views on information dissemination. Views ranged from the need for a basic level of consistent information between both parties to facilitate an accurate and shared expectation of the future (with caregiver access to additional information only when patient permission was granted), to caregiver preference for full access to information without patient censoring as recognition of their caregiving role.[19,44] In response, studies suggest staff need to be aware of potential changes in caregiver–patient discourse in line with factors like disease progression and differences in preference regarding ownership of information.[15,19,44] In addition, caregivers were found to be more accurate in estimating patient experience when encouraged to imagine the patient's feelings.[39]

Communication between caregivers and health professionals was a key issue in determining the adequacy of information provision and caregiver understanding. Quality of communication was found to be variable, particularly in relation to the level of detail of the information provided; this could result in poor caregiver knowledge and understanding.[13,45] It was found that caregivers frequently sought a personalized relationship with health professional as a means to facilitating staff understanding of their needs, including the need to talk freely about the disease and feel comfortable in raising difficult issues.[18,29] Deficiencies in communication related in particular to inadequacies in the amount of time given for discussion and the number of meetings between the caregiver and health professional. Where these deficiencies were met,

caregivers experienced increased reassurance, knowledge and an enhanced sense of control.[18] In response, health professionals should facilitate a proactive caregiver approach by offering opportunities for communication.[18] In addition, all health professionals should carry out an initial assessment of the caregiver perspective and the level of information desired.[45]

Information needs were reported to be a key component of caregiver coping strategies.[26,29] Studies identified disease-related information, including information that led to understanding of events that might indicate disease progression and death as the primary preference, followed by information relating to palliative care, social welfare, psychological issues and spiritual care.[23,38,44] One study identified inadequate information provision to be a weakness of community palliative care.[34] Access to high-quality information was associated with a decrease in anxiety due to enhanced perception of control.[32] Recommendations included the provision of information to meet the individual needs of caregivers in line with concerns and disease progression and the provision of information on community agencies.[34,38] In addition, information assessment instruments and support programmes should be developed to respond to caregiver information and communication needs.[26,29,38]

Specific groups of palliative care patients were found to experience particular dissatisfaction with services. Non-cancer patients (cardio-respiratory) were found to experience greater inadequacies in information provision and Black Caribbean patients expressed dissatisfaction with health professional communication and information provision.[20,33] In contrast, a study focusing on the experience of Bangladeshi patients who received community based palliative care, reported considerable satisfaction with health professional communication, although there were difficulties with translation where family members were involved.[43] Where family, as opposed to professional interpreters, have been used, this has generated concerns regarding the power of individuals to withhold information.[19] The article additionally highlighted the importance of understanding social dynamics and traditional values, including burial preferences and spiritual needs, in providing appropriate palliative care.[43] Positive experiences of health professional interaction were associated with good communication.[41] Negative experiences, as observed in one study of community hospitals, was associated with poor communication.[42] In general, recommendations focused upon the need for improvement in health professional communication skills,[41,42] the value of improved staff recognition of the varying needs of patients and caregivers in accordance with ethnicity,[33,43] and the value of increased staff training in the principles of inclusive palliative care.[33]

Four studies focused upon either the implementation or development of an intervention for caregivers in palliative care. Interventions included: a tool for defining and solving problems; identification of obstacles to effective care and subsequent adjustments; psycho-educational support to improve caregiver knowledge of delirium; a 90-minute group of informal multi-professional teaching and peer support; and a nursing intervention combining guidance and support.[17,24,25,28] Although a key focus of each intervention was to increase knowledge generally through the provision of education and information, weaknesses in method made it difficult to establish impact (there was typically no control group, and limited controlling of confounders) or generalizability (often, studies related to a single site).[17,25,28] Recommendations focused on the need for future rigorous evaluations of interventions.[25]

Discussion

A central goal of palliative care is the appropriate management of pain. This was strongly reflected in the evidence reviewed where a substantial number of papers examined the multiple barriers to pain management among informal caregivers and patients, frequently emphasizing inadequate knowledge, poor communication and lack of patient–caregiver consensus. As Ward, *et al.* have observed, 'these findings highlight the need for patient and caregiver education about reporting pain and using analgesics'.[46] Although educational and multidisciplinary approaches to targeting such barriers were outlined, these were small in number, limited to specific settings and weakly evaluated. Other caregiver information needs were also identified, such as knowledge of social welfare provision and spiritual support, but these were rarely addressed by professionals involved in the delivery of end of life care. This gap was additionally reflected in information assessment with limited development of caregiver-specific assessment tools.

The provision of information and support to caregivers has also been shown to vary according to patient disease type and ethnicity, creating inequities in care and barriers to the development of inclusive palliative care. Indeed it has been argued that certain minority ethnic groups 'will strongly favour home deaths because of the isolation in hospitals from poor communication, the differing food requirements and the desire to observe religious duties'.[43] This tendency, along with the compounding issue of socio-economic disadvantage faced by some minority ethnic communities, underlines the need to cater for the cultural diversity of caregiver needs. Although a small number of interventions responding to inadequacies in caregiver knowledge were identified, these were poorly designed and inadequately evaluated, offering limited recommendations.

The evidence base for understanding caregivers' knowledge and information needs in palliative care is

therefore limited. It is also disparate, in terms of topics covered, study design, outcomes and generalizability (in particular locally based studies). Methodologically, the evidence base is predominantly descriptive, based on small-scale studies and therefore frequently outside of the standard hierarchies of evaluation in medical research. There are few quantitative studies and no randomized controlled trials or controlled experimental designs, although there are particular concerns over conducting such trials in palliative settings.[47] Consequently, no study was able to determine causality in a statistically credible manner. Although a number of papers combined a qualitative and quantitative approach, triangulation of findings was limited. Sample sizes were generally small and in cases of repeated measurement, attrition rates were high, although this did not prevent some studies using inappropriate analytical techniques. A variety of validated and non-validated assessment tools were used creating difficulties with comparison. These combined factors significantly limit generalizability. However, this limitation was not fully recognized in the conclusions of some studies, where there was a tendency to apply findings to situations beyond the scope of the study.

However, there are also a number of strengths to the evidence base, which in many ways reflect the richness and diversity of approach characteristic of palliative care. The descriptive nature of findings offers an in-depth understanding of caregiver knowledge and information needs. The evidence base also embraces the diversity of palliative care settings and therefore the variation of associated caregiver needs. Although the methodological approach is weak when judged against standard medical research criteria, researchers in the field have been successful in developing techniques that reflect the sensitivity of end of life care, offering other medical specialisms examples of where a qualitative approach could be beneficial in understanding health care needs and experiences.

Conclusion and implications

Future research must address the weaknesses identified in the current review. As Irene Higginson has recently argued in relation to clinical research in palliative care, it would be nice to have a larger and more rigorously researched evidence base.[48] In relation to the focus of this review, a greater level of triangulation is required both within and between studies, which consider the needs of caregivers. Given the predominance of qualitative research in the field, further steps must be taken to enhance rigour, including triangulation through the use of multiple data sources, reflexivity, attention to negative cases and greater consistency in approaches to external and internal validity.[49]

Methodologically and conceptually, research in this field is dyad focused, frequently examining the relationships between two agents in the palliative care setting: patient–caregiver, patient–professional or professional-caregiver. This contrasts with the practice of palliative care itself, which is founded upon the idea of a holistic approach,[50] supporting an ongoing interaction and dialogue between the triad of patient, caregiver and service provider. The available evidence therefore suggests a discrepancy between the practice and overall philosophy of palliative care and the research methodologies used to study it, as illustrated in Figure 1. As care moves into patients' homes, where such three-way interactions will be a core feature of the practice of palliative medicine, it is important that researchers design studies that can adequately capture the complex dynamics of this situation. Without employing this more holistic approach, it is likely that the knowledge and information needs of informal caregivers will not be fully understood.

Alongside this conceptual omission, a number of significant gaps can be identified in the evidence base relevant to developing policy and practice. The majority of papers were concerned with the knowledge and information needs of caregivers of patients with cancer. As palliative care broadens to meet the needs of patients with other life-threatening conditions, it is necessary to undertake research to understand the experiences of these caregivers. Additionally, there were only a limited range of studies that sought to understand the dynamics of caring among

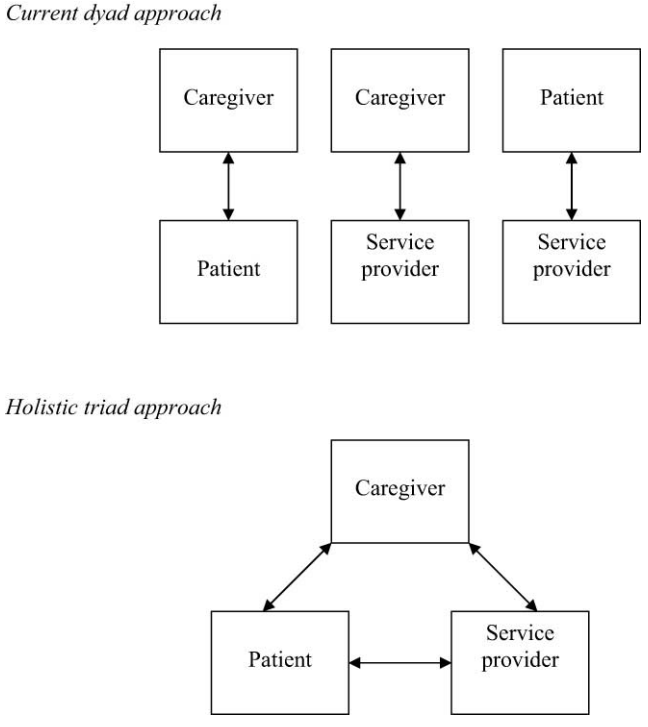

Figure 1 Dyad and holistic approaches to research design in palliative care.

minority ethnic people, where the interactions of culture, belief and palliative care may alter the patterns of caregiver need. This points to the importance of understanding the needs of all caregivers that are not directly related to the medical condition of the patient such as spirituality, social well being, finance and work-related needs. These factors should be incorporated within wider professional assessment of caregiver needs and be considered alongside more medicalized requirements such as knowledge of pain management. Finally, research, policy and practice must reflect the often complex and fast-paced changes to caregivers' roles and information needs associated with disease progression.[51] Service providers must incorporate all of the above within professional training to allow for caregiver needs to be appropriately matched to professional skills.

It is clear from this review that there are many issues that need to be addressed in order to provide an effective, efficient and responsive palliative care service, which meets the needs of all individuals involved in the triad of care. If the current policy in the UK of developing the provision of home-based palliative care is to be successful, we need to better understand the roles and needs of informal caregivers through:

- an improved evidence base utilizing a variety of appropriate methodological approaches deploying consistency in research design and evaluation;
- greater recognition of dynamics of care, including the patient–caregiver–professional triad and the implications of disease progression;
- increased focus upon, and rigorous evaluation of, caregiver specific knowledge-related interventions and needs assessment tools;
- enhanced training for those providing services to improve communication skills, develop cultural competence, improve understanding of non-cancer conditions and the non-medicalized needs of caregivers.

Contribution

AD, AO, MAL and RP undertook the search and review. AD, AO and MAL drafted the article. YHC, RP and JW commented on, contributed to and edited subsequent drafts. The study of which this article forms a part is co-directed by YHC and RP; JW is the Senior Researcher. YHC is the guarantor of the paper.

Ethical approval

Not required.

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